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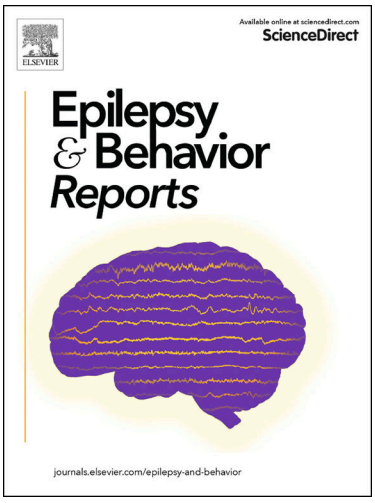


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# Frequently asked questions and answers on Visually-Provoked (Photosensitive) Epilepsy

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## Highlights

- Photosensitivity is the most common reflex epilepsy
- Patients and caretakers recognize circumstances that precipitate seizures.
- Questions on medical and non-medical issues have been collected and answered

# Abstract

Clinical experts associated with national epilepsy-related societies, led by the Epilepsy Foundation, collected, collated and answered "Frequently asked questions (FAQ)" of broad interest pertaining to visually-provoked seizures. Questions emerged from people with epilepsy, caretakers and healthcare professionals from different countries around the world. Focus is on practical implications of visually-provoked seizures. The top 5 most frequently asked questions were

1. How does a doctor make a diagnosis of visually-provoked seizures?
2. What can I do in general to prevent visually-provoked seizures?
3. Will I need antiseizure medications for my visually-provoked seizures?"
4. Will I outgrow visually-provoked seizures? How will I know if I've outgrown them?
5. How do I enable safety features to block content that could trigger seizures on social media, websites, phones, laptops and tablets?

Answers were based on scientific evidence, where such information was available [1] and expert opinion when formal evidence was insufficient. Key answers included distinction of photoparoxysmal EEG findings versus light-provoked seizures. Typical provocation is by flashes at 10-25 per second or certain moving patterns. There is a genetic risk, which is outgrown in about half. Covering one or both eyes can prevent a light-provoked seizure. TV, videogames, virtual reality and 3D images are not in themselves provocative, but their content can be.

Topics covered included: 1. Photosensitive epilepsy diagnosis; 2. Preventing visually-provoked seizures; 3. Do treatments help; 4. Life and behavioral decisions; 5. School; 6. Multi-media; 7. Children and youth.

***Keywords: Epilepsy; Photosensitive seizures; Pattern-sensitive seizures; Reflex Epilepsy; Video game seizures***

# Introduction

People are exposed to a variety of visual stimuli that could provoke seizures. Public knowledge is increasing but many questions remain unanswered, thereby creating unnecessary anxiety. Visually-provoked seizures occur in a minority of people with epilepsy, but they can affect people with all types of epilepsy and at all ages, although maximally during adolescence [2].

Visually -provoked seizures represent the most common type of reflex epilepsy. The incidence of people with new-onset seizures and a photoparoxysmal EEG response is 1.1 per 100,000, and 5.7 per 100,000 for age 7-19 [3]. Visually-provoked seizures affect 2% of all epilepsy patients and 10% of adolescents with epilepsy [1]. Prevalence of photosensitivity is high in certain epilepsy syndromes, particularly, juvenile myoclonic epilepsy, absence epilepsy, generalized tonic-clonic seizures upon awakening, Jeavons syndrome, sunflower syndrome and myoclonic epilepsies of infancy [1,4]

This article employs a question-and-answer (Q&A) format to provide easily accessible information about what photosensitive epilepsy means, how to interpret signs and symptoms related to potential provocative visual stimuli, and how to deal with it in daily life to decrease the risk of seizures.

# Methods

## Collection and processing of questions

The Epilepsy Foundation convened a working group on photosensitive epilepsy, including epileptologists from the United States (n=8), Europe (n=5), Asia (n= 1) and Australia (n=1) as well as a lawyer with expertise in epilepsy and a parent advocate. The group included 8 adult epileptologists and 7 pediatric epileptologists with a variety of expertise related to visually provoked seizures. Group members individually generated lists of questions based on clinical encounters with patients with photosensitive epilepsy and contributed these to a central database. This list was iteratively reviewed by the working group via virtual meetings in order to consolidate and organize the questions, which were then answered based on available literature and clinical expertise of group members.

An important limitation is that the authors did not directly have collected surveys from consecutive patients but rather relied on the collective clinical expertise of a large group of epileptologists with specific knowledge and interest in photosensitivity. A second limitation is that the working group did not include members from South America, Africa, Southeast Asia, or the Middle East.
The questions and answers will be made available via the Epilepsy Foundation website where there will be a form for people to raise additional questions that the working group will consider and integrate in future documents.
The top 5 most frequently asked questions were

1. How does a doctor make a diagnosis of visually-provoked seizures?
2. What can I do in general to prevent visually-provoked seizures?
3. Will I need antiseizure medications for my visually-provoked seizures?”
4. Will I outgrow visually-provoked seizures? How will I know if I’ve outgrown them?
5. How do I enable safety features to block content that could trigger seizures on social media, websites, phones, laptops and tablets?

Answers to questions given below are based on evidence from research studies when such data exists, as compiled in the open access review [1] by the same expert group.

This compilation of Q&A is general information, with terminology addressed to the general public. Some of the information is intentionally duplicative, on the presumption that readers will read only the FAQs of interest to them. No attempt was made to provide individual medical advice, for which consultation with a treating healthcare provider is necessary.

## Definition

Photosensitive epilepsy is a form of epilepsy in which seizures are precipitated by visual stimuli[5,6]. Light-induced seizures may co-exist with other types of seizures. The most provocative visual stimulus is flashing light. Occasionally, certain patterns or colors also can provoke seizures, usually patterns that include stripes or rapid color changes to and from red [7]. The likelihood of a seizure being provoked by flashing light depends on the flash frequency, with maximal risk usually in the range of 10-25 flashes per second, sometimes expressed as 15-20 Hz [3] . A combination of (colored) flashes and stripes typically is found in videogames and cartoons.

An EEG examination, with flashing light or other provocative visual stimuli, can detect a tendency to react to visual stimuli with seizures. This EEG finding, called a photoparoxysmal response or PPR [6], is not itself a seizure but indicates higher risk to having one with provocative light stimulation.

# Results

## 1. Photosensitive Epilepsy Diagnosis

### Q: What does my photosensitive epilepsy diagnosis mean?

A: In individuals with photosensitive (visually-provoked) seizures, seizures can be brought on by rapidly changing or flashing lights with high intensity and sometimes also by high contrast patterns, usually stripes, or by rapid color changes.

Some people are told that their electroencephalogram (EEG) shows changes when lights are flashed [7]. This can indicate a higher risk for having visually-provoked seizures.

**Q: What is the difference between photosensitive epilepsy and visually-provoked seizures?**

A: There is no difference between photosensitive epilepsy, light-induced seizures and visually-provoked seizures and the terms can be used interchangeably. Since many people think of skin sensitivity to light when they hear the word "photosensitive," and because some people are sensitive to patterns rather than lights, the term "visually-provoked seizures" is preferred.

**Q: How does a doctor make a diagnosis of visually-provoked seizures?**

A: Your doctor can make this diagnosis based on your history of seizures after exposure to light or to visual stimuli, such as seizures provoked by the sun flickering through a row of trees while driving in a car. If a doctor suspects visually-provoked seizures, they can order an EEG to look for confirmation following exposure to several frequencies of flashing lights. Most people with visually- provoked seizures will have a finding on EEG called a photoparoxysmal response [8], which presents as a build-up of brain electrical activity in synchrony with the light flashes. Figure 1 demonstrates an abnormal response, with generation of spike-waves, which can be associated with absence epilepsy.

**Q: I was told that my EEG showed I have photosensitivity and that I should avoid flashing lights, but I've never had a seizure triggered by lights. Was the test result wrong? Can I stop worrying about flashing lights?**

A: Some people, with and without epilepsy, will show an abnormal buildup of brain wave activity to the light flashes (photic stimulation) performed during an EEG. This is called a photoparoxysmal response or "PPR. [8] Not all people with PPR have visually-provoked seizures in daily life. A PPR is a risk factor for visually-provoked seizures, but does not mean that they will occur. If the frequency range to which you are sensitive is large, you are more at risk of having a visually-provoked seizure in daily life. Not everyone will react to the same

frequencies in the same way. Some people may also experience very small seizures and not be aware of having them.

If you had an EEG test showing a PPR, you should be cautious around flashing lights. If you are exposed to bright flashing lights, cover one eye with the palm of your hand. This can help because it diminishes the total amount of visual stimulus [9]. Simply closing your eyes (without using your hand as a cover) is less effective than is covering one eye with your hand, because your eyelids spread the light over a larger area of the retina (the back or inside wall of the eye that records the light stimulation). If lights bother you, consider avoiding the environmental light when possible or wear dark sunglasses.

**Q: In what situation(s) am I mostly likely to have a visually-provoked seizure? Are there any situations I should avoid?**

A: People with visually-provoked seizures have individual triggers. Bright lights that flash very quickly are the most common trigger. Lights that flash 10 to 25 (especially 15-20) [3] times per second tend to be the most likely to trigger seizures but some people have trouble with lights that flash as slowly as 3 times per second or as fast as 60 times per second (Figure 2 from [10]. The light has to get to both eyes and occupy at least a quarter of your visual space [11]. Lights that flash from red to other colors can be particularly triggering [12].

Some people are sensitive to patterns, such as moving stripes, zig-zags or expanding contracting circles that are common in music videos [5]. Certain video games can also provoke seizures in susceptible individuals [13]. People with visually-provoked seizures should be careful in discotheques, with sunlight flickering through trees, with shimmering sun on water and with certain videogames. People with epilepsy should be aware of their individual triggering factors. It is also good to have some lights on while watching television in order to reduce screen contrast, and to take breaks about every 30 minutes when playing video games.

**Q: What types of epilepsy are most at risk for visually-provoked seizures?**

A: Any type of epilepsy can be associated with visually-provoked seizures but the risk is higher for those with generalized epilepsies [2], which are often inherited seizures. The risk is fairly low for people with focal epilepsy, where seizures start

in one part of the brain, unless the seizure onset is in the occipital lobe, which is the part of the brain that relates to vision. People with epilepsy syndromes, such as Juvenile Myoclonic Epilepsy and rare conditions including Dravet Syndrome and Progressive Myoclonus Epilepsy, are especially susceptible to visually-provoked seizures [14].

**Q: What is Sunflower Syndrome?**

A: Sunflower Syndrome [17,18] is a type of epilepsy where visually-provoked seizures are very common. It is more frequently seen in girls than boys and tends to start between 2 to 8 years of age. Rather than avoiding light stimuli, affected children typically look towards a light source, usually sunlight, then raise one arm and wave their fingers in front of their eyes during seizures. Most patients consistently wave the same hand with all seizures [19] . It is unclear if the hand waving induces the seizure or is part of the seizure itself [20,21] Hand-waving is associated with blinking or eye fluttering with or without further evolution to other seizure types such as absence or generalized tonic-clonic seizures[19, 21] Seizures are often resistant to antiseizure medications, although valproate [21] and fenfluramine [22,23,24] may be helpful. Other treatment approaches include lifestyle changes, such as wearing hats with wide brims or sunglasses when exposed to sunlight [17]. Novel use of wearable devices show promise for quantifying seizure control [25]. The frequency of handwaving episodes and light seeking behavior usually decreases as the patients grow older.

**Q: Am I always going to have visually-provoked seizures? When I was younger, I didn't have it. Does it come and go over time? I read somewhere that about 25 percent of people who have visually-provoked seizures will outgrow them in their 20s, but I read somewhere else that 80 percent will. Which do you think is right?**

A: Visually-provoked seizures are most common in children and adolescents and sometimes continue into adulthood [17]. Most studies find that more than half of people with visually-provoked seizures in childhood outgrow them in adulthood [18]. An EEG test can be done with flashing light to help your doctor detect if you have outgrown visually-provoked seizures.

**Q: Can visually-provoked seizures be dangerous?**

A: Visually-provoked seizures, like any seizures, can be dangerous. Most seizures are not dangerous but injuries can result from lapses of awareness or falls.

Visually-provoked seizures are most likely to be dangerous if they happen during an activity where losing awareness—such as driving or being in the water—could be deadly. If your hobbies include activities where you see sunlight flashing on water or snow—such as swimming, fishing, sailing or skiing—make sure to wear dark glasses and hats with brims.

**Q: I have visually-provoked seizures. Will my child?**

A: Your child is at higher risk of having visually-provoked seizures. One study showed that children of women with visually-provoked seizures have a 25% chance of demonstrating an abnormal response to light flashes on EEG. However, only half of these go on to develop epilepsy [19].

**Q: If I am sensitive to flashing lights, am I also sensitive to patterns, and if so, which ones?**

A: Among people with visually-provoked seizures, most are sensitive to bright lights that flash 10 to 25 times per second. About one-third of people who are sensitive to flicker are also sensitive to high contrast patterns, usually stripes [20]. When the pattern vibrates, the sensitivity is higher than when the pattern is still. If you look at the pattern and hold your finger at arm's length the worst patterns have 1-10 stripes under your fingernail (more simply stated patterns in which many stripes are packed rather closely). Avoid these patterns.

**Q: The seizures I have that are triggered by lights are different from my seizures that start for no apparent reason. Why is that? Should I expect that this will always be true?**

A: The sensations and appearance of seizures depend on several factors. Among the most important are the location in the brain, where the seizure activity starts, and the paths taken, as the activity spreads through the brain. Visually-provoked seizures arise through the occipital cortex (back part of the brain) which is the vision control region of the brain [21]. A visually-provoked seizure may take a different path and look and feel different from your typical seizures. Most likely, this pattern will hold true over time. Sometimes seizure treatments, such as medicines, surgery, ketogenic diet or neurostimulation, affect one of your seizure types more than another.

**Q: I get headaches from bright lights. Does that mean I have visually-provoked seizures?**

A: Not necessarily. Some types of headache, like migraines, can be triggered by bright lights. Most people who have headaches with bright lights only have a headache disorder and do not have epilepsy.

Some people with visually-provoked seizures also have migraines [22]. Many people with seizures have headaches after a seizure ends. Very rarely, headache is the only symptom of a visually-provoked seizure. In such cases, your neurologist or epileptologist can evaluate whether an antiseizure medication may be helpful. Some antiseizure medications are also useful to treat headaches when there is no history of seizures. This is something you should discuss with your doctor.

If lights cause or worsen your headaches, consider wearing dark glasses (sunglasses) [23] when you go somewhere where there will be bright lights. If flashing lights cause headaches, cover one eye with the palm of your hand, as described above.

## 2. Preventing Visually-Provoked Seizures

**Q: What is the simplest, most effective way to reduce the likelihood of a visually-provoked seizure?**

A: Try to avoid situations that you know provoke your seizures. If confronted by flashing lights or provocative patterns, cover one eye with your hand and leave the situation. If possible or safe to cover both eyes and leave the situation, you could alternatively cover both eyes. Closing your eyes without covering them does not block enough of the light and may make matters worse.

**Q: What can I do in general to prevent visually-provoked seizures?**

A: If you have a genetic predisposition to visually-provoked seizures [24], they are most likely to occur in childhood or around the time of puberty. You can decrease this risk by the following:

- Make sure you have enough sleep;
- Minimize stress;
- Do not use stimulant drugs, like cocaine or methamphetamine;
- Take your antiseizure medications as prescribed; and

- Reduce daily exposure to flashing white and colored lights from television and video games.

If you know the type of lights or patterns to which you are sensitive (for example, bright flashing lights or certain patterns), avoid these whenever possible. Try to avoid music festivals, parties or nightclubs where there are flashing white and colored lights. If you are exposed to these lights, cover one eye completely, using the palm of your hand and look away [9]. Simply closing your eyes (without using your hand to cover one eye) is less effective because your eyelids spread the light and make it even more provocative. Covering both eyes is most effective, but will prevent you from safely walking away from the environment in which the lights are flashing or striped patterns are in abundance.

Turn down brightness and contrast on the TV or videogames, turn on lights when watching TV or playing computer games to reduce contrast, sit at least 6 feet from the TV screen and take long gaming breaks every 30 minutes.

**Q: Does the flashing of mobile phones provoke seizures?**

A: Very bright flashes from cell phones held close to the face can cause seizures [25] but this happens only rarely because of the small screen size.

**Q: Do dark blue glasses protect people from having visually-provoked seizures?**

A: People with visually-provoked seizures, including seizures provoked by bright patterns, can sometimes benefit from colored glasses.

There is some evidence that the most effective color lenses vary from one person to another, for example, turquoise (a bluish color) [23]. To see what color is most comfortable for your eyes, you might consider trying colored lenses in a variety of colors, first at the optician or in a retail store or consider contacting an optometrist who uses the *Intuitive Colorimeter*. *Intuitive Colorimeter* is an instrument that allows you to change the hue (color) and saturation (strength of color) separately and without changing brightness (luminance). For more information, see https://ceriumvistech.com/international-list-of-specialists/.[i]

Colored glasses do not help everyone. Using darker, polarized glasses can provide additional protection. The Epilepsy Foundation does not promote specific products,

but searching the web for "colored glasses" will bring up dozens of items, ranging in cost from $15 to $300.

**Q: I don't want to wear dark glasses all the time. Would blue contact lenses work just as well?**

A: Some people have tried blue contact lenses with good results but, as with the glasses, long-term use might affect color vision, although there is currently no research data on this. For those who drive while wearing blue lenses, caution is advised because blue lenses may obscure orange or yellow traffic signals.

## 3. Do Treatments Help?

**Q: When are antiseizure medicines needed for visually-provoked seizures?**

A: You should discuss the best approach with your medical team. In some cases, if you only have visually-provoked seizures, you can try to avoid flashing lights or other triggering visual patterns. Whether or not you are able to avoid flashing lights or triggering patterns, antiseizure medications may also be needed [26].

**Q: Is there any role for behavioral therapy?**

A: Cognitive Behavior Therapy (CBT) has been reported to improve depression in people with epilepsy, but not necessarily seizure control [27] . Efficacy of CBT for light-provoked seizures is unknown.

## 4. Life and Behavioral Decisions: What Should I Not Do? What Can I Continue Doing?

**Q: Does everyone with epilepsy have to avoid flashing lights?**

A: No, only if your experience or an EEG test suggests a tendency toward visually-provoked seizures. Only about 3% of people with epilepsy are visually-sensitive [18]. Some epilepsy conditions are more prone to photosensitivity than are others.

Ask your healthcare team about your risk for visually-provoked seizures if you have one of the following conditions; the percentage of people with each condition who have visually-provoked seizures appears in parentheses [1]:

- Juvenile Myoclonic Epilepsy (30%-90%)
- Childhood (18%) and Juvenile (8%) Absence Epilepsies
- Generalized Tonic-clonic Seizures on Awakening (13%)
- Dravet Syndrome (40%)
- Benign Myoclonic Epilepsy of Infancy (10%)
- Epilepsy with Eyelid Myoclonia including Sunflower Syndrome (100%)
- Focal photosensitive occipital epilepsy (100%)

**Q: What activities can I not do?**

A: Safe activities depend upon the nature and frequency of your seizures. What is safe for one person with epilepsy may not be safe for another. Most restrictions can be determined by common sense and apply equally to all types of seizures. There are certain considerations that are specific for visually-provoked seizures including:

- Try to avoid locations with flashing or strobe lights, including discotheques, clubs, raves, concerts with bright strobes, arcades or amusement parks. If you are exposed to a flashing or strobe light unexpectedly, look away and cover one eye completely with the palm of your hand.
- Avoid stimulating drugs like cocaine or methamphetamine.
- Driving (if allowed by regulators) may require wearing dark polarized sunglasses. When you drive past tall objects, like a row of trees, the light can take on a flashing quality and cause seizures.
- Activities where you see sunlight flickering on water or snow—such as swimming, fishing, sailing or skiing.

**Q: Is there a way for me to "test" if that activity is safe?**

A: It is not worth risking a seizure with a "test." An exception is photic stimulation during an EEG, which gives you an estimate of your risk and is performed within a medical facility, should you have a seizure and need help. When you repeatedly notice symptoms like jerks and strange feelings in the head or eyes, at the same time that your EEG shows an abnormal buildup of brain wave activity, called photoparoxysmal response (PPR) [6], it shows you are at a high risk for visually-provoked seizures. During everyday life, you can then pay attention to what causes the same feelings and learn to avoid these devices or situations. It is important to discuss this with your treating physician.

**Q: Can I drive even though I have brief seizures with retained awareness?**

A: Every state in the U.S. regulates driver's license eligibility of people with certain medical conditions [28]. In Europe and other continents like Japan and Australia state regulations are in place with variations as well. The most common requirement for people with epilepsy is that they should be seizure free for a specific period of time (typically varying from 3-12 months) and submit an independent physician's evaluation of their current seizure control.

Most states in the U.S. have DMV Medical Advisory Boards to consider exceptions to license suspension for seizures. First, see if your medical care team agrees. Then have your medical team fill out a form with recommendations to your state's health department or DMV. It is important to realize that even if you feel like you retain awareness during such episodes, this is not always the case. Discuss this with your treating physician.

**Q: What jobs / work environment should I avoid?**

A: Most people with epilepsy can work at meaningful jobs [29]. It is worth noting that a few career choices are strictly denied (with occasional special exceptions) to people with epilepsy, such as being a commercial pilot or joining the armed forces or police. For some jobs, an individualized assessment may be necessary to ensure that a person with epilepsy is qualified to safely perform that job. For more information about employment with epilepsy, visit https://www.epilepsy.com/lifestyle/employment.

**Q: Is flying / traveling OK with visually-provoked seizures? How about jet-lag?**

A: Flying as a passenger usually is safe, but patients with frequent seizures may report more seizures within a week of a flight [30]. Disruption of your typical sleep pattern or sleep-deprivation – including due to jet lag – are provocative factors for many people with seizures. It is advisable to avoid flights in a helicopter because the rotors can interrupt sunlight, causing flicker in the cabin. Seek advice from your medical team about how to shift the schedule of your antiseizure medications.

**Q: I have visually-provoked seizures: Are police lights dangerous?**

A: Some people report that red-blue flashing police lights trigger seizures but people typically need to be very close to the lights for this to happen. Testing in an EEG laboratory shows that risk of modern police light bars appears to be low [31].

The lights may be more likely to trigger seizures at night when the contrast between the darkness and the bright lights is greatest.

**Q: Should individuals with epilepsy avoid watching fireworks?**

A: Fireworks have been reported to provoke seizures [32], but this is not common. It might be safe to watch with one eye covered or wearing dark glasses.

**Q: Is it better to have the light on or off in the room while watching TV or playing video games?**

A: Having room light on can be better because it reduces contrast with the screen. For some people, this does not make a difference.

**Q: Which is more of a problem when flashing, direct light or diffused light?**

A: Diffused flashing light is much more provocative than direct light because a larger area of the retina (the back or inside wall of the eye) is stimulated. It very much depends on the viewing situation itself (screen size and type, viewing distance, and environmental lights). Closing your eyes (without using your hand to cover one eye) can diffuse flashing light through the eyelids—which can make things worse because it spreads light over a larger area of the retina, increasing sensitivity and the effect that causes seizures. Covering one eye with an eye patch or wearing dark glasses may prevent a light-induced seizure.

## 5. School

**Q: Are there reasonable accommodations for students with visually-provoked seizures?**

A: In the United States, students K-12 are protected from disability discrimination by three federal laws. The Individuals with Disabilities Education Act (IDEA) - which requires an individualized assessment of the needs of each student's - provides both non-discrimination and reasonable accommodations to maximize the learning potential for every student with epilepsy. The assessment produces an Individualized Education Plan (IEP) that guides the child's education experience. In addition, both the Rehabilitation Act (for schools that receive federal money) and the Americans with Disabilities Act (ADA) (public and private schools that are not wholly religious) provide protections for students with epilepsy.

Under each of these laws, the process begins with the parent or caregiver requesting the accommodations. Once a student moves on to college, the federal protections of the Rehabilitation Act (where the school receives federal funding) and the ADA (for public and private colleges and universities that are not wholly religious) remain with the student. The student (now an adult) should approach the disability office to begin the process of pursuing needed accommodations. Accommodations for any educational experience may include extra time, less use of a computer, a note taker, writing out an exam longhand, as opposed to on a computer, and wearing a medical device in certain settings, among others. It might also include advance notice of fire alarm drills in class or the dorm because U.S. fire alarms produced slowly flashing lights that are able to alert hearing-impaired individuals.

**Q: Can I go to college with visually-provoked seizures?**

A: Yes, but some preparation may help you stay safe while also enjoying your studies. College often is a time when young adults take on new levels of personal and academic responsibility. There are scholarships for which you may be eligible specifically for people with a diagnosis of epilepsy. To make the most of your college experience, you should be aware of common seizure triggers in the college environment, including stress, sleep deprivation, strobe lights, video games, and alcohol/other recreational substances. Plan ahead to make sure your course load and other responsibilities still leave you time to get adequate sleep.

Think about with whom you'd feel comfortable talking about your epilepsy. Consider how you will handle situations where others are using alcohol or other recreational substances which you should avoid (particularly stimulant drugs like cocaine or methamphetamine). The following resource may help you as you plan for your advanced schooling: https://www.epilepsy.com/parents-and-caregivers/work-college/attending-college.

**Q: Can I stay up all night if I need to do school work or want to go to a party? Is it ok if I sleep in or "make-up" the sleep later?**

A: Sleep deprivation can be a major trigger for many types of seizures [33]. "Catching up" on sleep may not protect you. Some studies have found that when people with photosensitivity are sleep- deprived overnight and then take a short nap, they are actually more sensitive to flashing lights when they wake up from the nap. This is because many generalized seizures are most likely to happen in the early morning hours or soon after awakening from a nap. For all these reasons, it is

best to try to get a full night (about 8 hours) of sleep every night and to keep a consistent bedtime and wake-up time. Consistently getting a full night's sleep also can help you think better and can protect against many other health problems. Creativity in adapting to the circumstances can help, such as organizing a costumed ball and wearing a pirate outfit (one eye covered!).

**6. Multi-Media**

**Q: I have to worry about seizures in so many situations. How can there be so many things in the environment that can give me a potentially harmful seizure?**

A: If you are careful and prepared, you should not need to worry. If you unexpectedly encounter bright flashing, cover one eye as quickly as possible to prevent a seizure (Note: don't just close your eyes because your eyelids let in some light). If it is safe, you can also cover both eyes. Try to avoid the environmental trigger when possible and stay prepared by keeping dark glasses handy. Most people find these glasses prevent seizures or reduce severity but if they aren't helping you enough, try polarized lenses or a darker tint.

If you've been seizure-free long enough to be allowed to drive, wear dark glasses while driving but remember that driving at night with dark glasses is not recommended. Be aware that dark or colored glasses may make it hard to notice orange or red traffic lights. If you're venturing into nature, bring your glasses and pay attention to your surroundings. Look away or cover one eye if you see lightning, light flickering through trees or sun reflecting off water or snow.

Electronic devices are one of the most common causes of visually-provoked seizures. Media increasingly involves 3D imagery and virtual reality. No large studies have addressed safety issues but published experience suggests that these are not a major risk for provoking seizures [34].

**Q: Is anything being done to make things like TV and video games safer for people like me?**

A: Screen use in general is becoming less risky because users have more control over what they see on screen and newer TV screens and computer/gaming monitors are much less likely to produce constant flicker at a triggering frequency. High Definition (HD) and curved TVs are riskier. High definition—or 1080P TVs—have a horizontal arrangement of 1920 Pixels, a vertical arrangement of

1080 pixels across the screen and a 16:9 widescreen picture aspect ratio. While not that different from flat TVs, in terms of viewing angle, curved TVs have a slightly curved display panel offering an "immersive" viewing experience (see Keerthi. (2023, April 28). *10 Types of Television: By Tech, Resolution and Screen.* Styles at Life. https://stylesatlife.com/articles/different-types-of-televisions/.)

Safety features for people with visually-provoked seizures are available in some web browsers, cell phones and major social media platforms, letting users opt to disable autoplay and to block potentially seizure-inducing content. Some video games provide options, within the game, to adjust the display intensity. On TVs and gaming monitors turning down the brightness setting helps. Several countries–but none in North America–require TV programs and advertising to meet strict guidelines for reducing the risk of visually-provoked seizures.

TV show directors and producers and video game designers like to produce designs that are visually striking and this means that they overstimulate the brain, while often also considering safety features. In many cases, specific warnings are given at the beginning of a show or game.

**Q: My EEG did not show that I have visually-provoked seizures, but I have had seizures sometimes while playing video games. What does that mean?**

A: Some people who have seizures from video games do not show evidence of visual sensitivity when tested in the EEG lab. This can happen if:

- The photosensitivity testing didn't follow standard procedures carefully.
- The test procedure didn't expose you to something very specific about the motion or colors in certain games that trigger your seizures. Try repeating the EEG while you play a video game that leads to seizures.
- You played video games under conditions that increased the risk of seizures, such as being sleep-deprived, ill, stressed, hungry or playing for a long time without taking breaks. These factors, rather than the video game, could be causing seizures.
- The episodes you experience, during video games, are non-epileptic (functional, psychological) seizures, which EEG doesn't detect. Although non-epileptic seizures look and feel a lot like epileptic seizures, the way they happen in the brain is different. Video EEG of an episode is useful to make that diagnosis.

**Q: Is watching TV dangerous if I have visually-provoked seizures?**

A: Watching TV or computer screens is not in itself dangerous. Most modern TVs and computer monitors are safe, although high-definition (HD) curved televisions (described above) and large screens should be avoided. It is the content of the TV or computer program that determines risk. Sitting close to a large screen in a dark room with bright screen pictures and repetitive flashes, lots of fast cuts between scenes or moving "barber-pole" patterns can provoke seizures in susceptible individuals. Movies usually are not bright enough to provoke seizures, with rare exceptions. In a theater, sitting close to the screen raises risk, but at home, large, bright screens increase risk substantially.

**Q: Is there a difference in the risk of visually-provoked seizures between different types of televisions? Is there any kind of TV that reduces the risk?**

A: Yes, the type of TV screen affects the risk of visually sensitive seizures. The old cathode ray tube televisions are a far greater risk than the modern screens. HD and curved TVs—which are described above—produce a stronger and larger visual stimulus and they have a higher risk. There are technological developments in preparation to reduce risks of shown programs, but these need to be tested in a larger population. The effect of LEDs, on people with epilepsy, is a subject that would benefit from additional research.

**Q: Does the distance from the TV play a role in reducing the risk of seizures?**

A: Yes. The further you are from the TV, the smaller the image of the TV screen on the retina (the nerve cells in the back of the eye) and the lower the risk of seizures. This is true for any display screen, including movie screens, as well as any source of flashing and/or patterns. To reduce the risk, you should stay at least 6 feet away from the screen or at a distance 3 times the width of the screen.

**Q: Do movies in theaters cause visually-provoked seizures?**

A: Not very often because most films are relatively dim. However, movies are getting brighter and are more likely to provoke seizures in the coming years. The Epilepsy Foundation has requested that movies with strobe-light effects post warnings.

**Q: Are there laws mandating warnings for people with visually-provoked seizures before movies and TV shows?**

A: In the United States, there is no provision in federal law requiring a warning to consumers of flashing lights in television shows that may prove problematic for those with photosensitive epilepsy. In the UK and Japan, broadcasting guidelines are available, to prevent potentially provocative TV sequences, but these are non-binding.

Many film studios and video production companies use vetted tools or trained human testers to check for photosensitive content in film and video games. Streaming services and theatres often include a warning at the beginning of a production if there is photosensitive content.

**Q: Does watching a movie in the cinema instead of at home change the risk of seizures?**

A: There is no clear data on this yet.

**Q: Can I work at a computer if I have visually-provoked seizures?**

A: Yes. Avoid those with pulse width modulation (PWM) which turns the screen on and off continually and varies the proportion of time when on in order to adjust the brightness. https://www.notebookcheck.net/Laptop-Buying-Guide-Tool.13212.0.html.

**Q: How do you enable safety features to block content that could trigger seizures on social media, websites, phones, laptops and tablets?**

A: Some content, like GIFs and videos with strobe effects, can trigger seizures. Reducing contrast and brightness on your device can help. On many devices and social media platforms, you can turn off or disable autoplay or take other actions to limit your risk of exposure to potential seizure-inducing content. Instructions on how to do this vary, based on the specific platform or device you are using. Below are some common examples of how to turn off or disable such content—but be sure to research steps on your particular device.

- How to Dim Flashing Lights on an iPhone
- How to Avoid Flashing Lights on an Android
- How to Disable Autoplay on Facebook
- How to Disable Autoplay on Twitter (scroll down to the section labeled "Watching videos on Twitter" for the steps to turn off autoplay)
- Accessibility for Watching Videos on TikTok

- How to Turn off Autoplay on Instagram
  - (On your smartphone) go to your profile.
  - Tap the hamburger icon on the top right and tap “Settings.”
  - Tap “Account,” then “Cellular Data Use.”
  - Now toggle the “Use Less Data” to switch it on.
- How to Disable Autoplay Previews on Netflix (Scroll down to the section labeled "Autoplay Previews while Browsing on All Devices" for the steps to turn off autoplay)
- How to Allow or Block Media Autoplay in Firefox
- Google Chrome:
  - Open a Chrome window and enter “chrome://flags/#autoplay-policy”
  - Next to “Autoplay policy,” change “Default” to “Document user activation is required”
  - Relaunch browser

**7. Children & Youth**

**Q: Will I outgrow this? How will I know if I’ve outgrown it?**

A: Many children may outgrow visually-provoked seizures but the chance of outgrowing them depends on the specific type of epilepsy [20].

If you become seizure-free while on antiseizure medications or the ketogenic diet, you may have outgrown visually-provoked seizures or the therapy may simply be controlling them.

The best way to know, if you have outgrown visually-provoked seizures, is to wean off your antiseizure medication(s) or stop dietary therapy and see if you remain seizure free; this must be done in consultation with your treating healthcare provider. Do NOT change your treatment without first talking to your doctor. EEG recordings during and after completion of treatment withdrawal can test ongoing sensitivity to light.

If you have a driver’s license and with your doctor’s approval, decide to wean off antiseizure medications, it is likely that you will have to stop driving during the time you are weaning out the medicine and maybe for a period after you have completely weaned out the medicine. Some driving authorities will not allow a person diagnosed with epilepsy to drive during the period of weaning out medication, in case this provokes a seizure and places the driver and other road

users at risk. Some authorities will extend the driving prohibition for a set period, following the removal of antiseizure medication, to be sure that it is safe to drive without the medicines on board. Check the local rules with your doctor or driving authority. It is very important to talk to your doctor about this.

**Q: My child has epilepsy. Should video games be forbidden?**

A: Most children with epilepsy don't have visually-provoked seizures and they can safely enjoy video games, 3D video games, movies, music videos, television and virtual reality. However, it is clear that some video games can evoke seizures in some players [35] . You should discuss the safety of these technologies with your child's epileptologist or neurologist. The proportion of individuals with epilepsy who have visually-provoked seizures is 3% (0.03-30% depending on the type of epilepsy). It depends on a variety of factors, including precise history taking and photic stimulation procedure during the EEG. Children who have had seizures in the presence of visual stimulation and those with photosensitive occipital epilepsy or epilepsy with eyelid myoclonia (Jeavons Syndrome, Sunflower Syndrome, or eyelid myoclonia with absences) need to follow certain guidelines to reduce their risk from these activities :

- Use smaller screens;
- Turn down screen brightness and turn on room lights to reduce contrast
- Stay at least 6 feet away from the screen or at a distance 3 times the width of the screen;
- Limit screen time and take frequent breaks; and
- Do not use screens when tired or sleep deprived.

Parents and children should also consider their pediatricians' recommendations, regarding healthy limits for screen time, to promote general health and particularly focus on not allowing screen time to interfere with sleep.

**Q. How many hours can I let my child play video games? Is it less risky to play in the morning, in the afternoon, or in the evening?**

A. The risk is lower when playing these devices while well rested, which may make the risk higher at nap times or in the evening. Hunger, thirst and stress may make your child more susceptible to seizures. There is no way to know, for sure, how your child will respond to specific visual stimuli. Your child may encounter unusually strong visual stimulation, after playing a game for a short time, and visually sensitive seizures can occur after very brief exposure to the stimulus.

Videogame induced seizures can also occur in those who are not photosensitive; in that case complex cognition-guided tasks are the trigger.[45]
You can reduce the overall risk of your child having a seizure, while playing with videogames, by limiting the screen time and by taking frequent breaks.

# Summary

Visually-provoked seizures can be recognized, investigated with an EEG and, to a certain extent, prevented. This document is based on real-life frequently asked questions by caretakers, patients and health professionals. Top 5 FAQs

1. How does a doctor make a diagnosis of visually-provoked seizures?
2. What can I do in general to prevent visually-provoked seizures?
3. Will I need antiseizure medications for my visually-provoked seizures?"
4. Will I outgrow visually-provoked seizures? How will I know if I've outgrown them?
5. How do I enable safety features to block content that could trigger seizures on social media, websites, phones, laptops and tablets?

The answers are meant to create awareness and help the community to deal with this specific phenomenon. Answers given are generalizable, but individual differences exist.

Ethical Statement
Ethical review was waived for this study

## Disclaimer

Reference to any specific commercial products, process, or service does not constitute or imply its endorsement, recommendation, or favoring.
Dr. Arnold Wilkins invented the Intuitive Colorimeter and has donated profits to the University of Essex to support students.

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Figure 1. Flash-induced spike-waves.

Figure 2. Percentage of people with light-provoked seizures who show a photoparoxysmal response at different flash frequencies. Most are between 10-25 Hz, especially 15-20 Hz. With permission from Epilepsia [10].